

# Information regarding the storage and use of your personal and health-related data when using the Swiss Testis Cancer Consult second opinion portal

# Dear Patient,

Swiss Testis Cancer Consult is a platform where patients and their physicians can receive advice from Switzerland's practicing experts in testicular cancer, or germ cell tumor, on the best possible way to diagnose, treat, and follow-up testicular cancer. Swiss Testis Cancer Consult's specialists are all physicians who provide their services in Switzerland and are bound to medical confidentiality.

The advice is given in the form of scientifically based second opinions. This means that it is still your physicians who are responsible and liable for your treatment. We only inform you and the physicians who treat you about what seems to be the best possible approach as far as diagnostics, treatment, and follow-up are concerned.

The consultation is free of charge both for you and for your treating physicians.

It may happen, however, that we will recommend you to seek out an expert center that is particularly specialized in the diagnosis, treatment, and follow-up of testicular cancer. Whether or not you choose to follow this recommendation is, of course, always up to you and your treating physicians.

To prevent any confusion during the consultation and to provide it as conscientiously as possible, we need to learn some key information on your disease and health situation, which we will keep on file for the documentation and monitoring of the disease progression.

This includes personal information (surname, first name, date of birth, social security number). Health-related data comprises histological (tissue sample) findings, lab test results, X-ray images, and medical reports, as well as information on major concomitant diseases, if any, which was collected when evaluating your condition. It also refers to information that describes the progression of your disease, and your body's response to any therapies performed, which is usually compiled in medical reports.

Such information will be stored in Switzerland as required by its data protection laws and will neither be disclosed to any third party nor used for any commercial purpose whatsoever. It is only available for consultation by Swiss Testis Cancer Consult's experts.

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# Swiss Testis Cancer Consult (SwissTeCC)



Nevertheless, in order to document the progression of your disease and treatment, we will from time to time ask your treating physicians whether or not and how your treatment was carried out, as well as whether or not it was successful in the long run. We do so in order to evaluate the quality of our consultancy services and, of course, to determine whether or not our advice was useful for your treatment.

# Will the information collected be used for research purposes ?

Swiss Testis Cancer Consult primarily aims at advising patients and their physicians. It is intended, however, to use the information collected at a later stage to perform so-called healthcare services research, i.e. to find out whether or not testis cancer patients in Switzerland really do receive the best possible treatment. Such healthcare services research is, of course, anonymous, and subject to prior approval of the research plan by a Swiss ethics committee. You can give your consent to, or decline permission for, the use of any information that may have been stored about you for this purpose.

### Do I have a right to access my data?

Yes. You can at any time contact Swiss Testis Cancer Consult to inquire about what information is stored about you.

### Do I have a right to revoke my consent?

Yes. Once you revoke your consent, any information stored about you will be deleted. In that case, however, we will not be able to provide you or your treating physicians with any further advice.

### Please read this information carefully and make your decision by checking the appropriate box.



I have read the foregoing and agree that information on me and my health may be stored by the Swiss Testis Cancer Consult portal.



I agree that Swiss Testis Cancer Consult's experts may from time to time request follow-up information from my treating physicians.



I agree that the information stored may be used for healthcare services research in anonymized form, so that it is no longer possible to identify me as an individual when evaluating such information.

Signature